

BNSSG CCG Governing Body Meeting

Date: Tuesday 7th January 2020

Time: 1.30pm

Location: The Vassall Centre, Gill Avenue, Downend, Bristol, BS16 2QQ

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| Agenda Number : | 7.2 |
| Title: | Learning Disability Mortality Review (LeDeR) Quarterly Report |
| Purpose: For Information | |
| Key Points for Discussion: | |
| <p>The report focuses on the following areas:</p> <ul style="list-style-type: none"> • The BNSSG CCG LeDeR activity for Q1 and Q2 2019/20 including progress made in meeting its KPIs and KLoEs in embedding the LeDeR programme across BNSSG CCG. • Progress made in recruiting and supporting reviewers with further work required to recruit more reviewers to be able to meet the KPI for allocating reviews within 10 working days and completion within 6 months. This includes the importance of whole system sign up and engagement with supporting reviewer sustainability across the BNSSG footprint. • Policy and guidelines on completing a Multi-Agency Review and a proposed model for sharing of learning throughout the BNSSG wider system. • LeDeR cases reviewed to date evidence six main learning themes being presented to the LeDeR steering group for recommended action. | |
| Recommendations: | The Governing Body is asked to note the findings in the report and the recommended next steps planned by the Steering Group |
| Previously Considered By and feedback : | BNSSG LeDeR Steering Group BNSSG CCG Quality Committee |
| Management of Declared Interest: | The CCG's Declarations of Interest process has been completed by all members of the LeDeR steering group. |
| Risk and Assurance: | The actions taken to date for improving the recruitment and retention of LeDeR reviewers have been successful, but further support is needed from all BNSSG organisations to provide named staff as LeDeR reviewers. Without organisational and whole system sign up and engagement there is a risk of not meeting the KPI requirements of allocating reviews within 10 working days and sustaining the completion of reviews within 6 months. This will |

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| | affect the ability of the wider system across BNSSG STP to take and embed learning from LeDeR reviews |
| Financial / Resource Implications: | To date the BNSSG CCG have been able to support compliance in the completion of LeDeR reviews using funding from NHS England to employ two dedicated LeDeR reviewers until 31 March 2020. The delivery of the LeDeR programme requires continued funding. |
| Legal, Policy and Regulatory Requirements: | There are no legal requirements in this paper |
| How does this reduce Health Inequalities: | Reducing health inequalities for people with a Learning Disability across BNSSG and improving access to services |
| How does this impact on Equality & diversity | LeDeR programme covers all deaths of people with Learning Disabilities over 4 years regardless of background. |
| Patient and Public Involvement: | Service user forum is in development to support and inform the work of the LeDeR Steering Group. A plan has been devised on how meaningful engagement from service users with the Steering Group can be achieved. Further update on this will be discussed at subsequent Steering Group meetings. |
| Communications and Engagement: | Not required for this paper. |
| Author(s): | Jenny Thompson Lead Quality Manager MH/LD/LeDeR Bridget James Associate Director of Quality |
| Sponsoring Director / Clinical Lead / Lay Member: | Rosi Shepherd, Director of Nursing & Quality |

Agenda item: 7.2

Report title: BNSSG Learning Disability Mortality Review (LeDeR) Programme Quarterly Report Q1 and Q2 2019/20

1. Background

This report is the first quarterly activity report relating to the learning from deaths of people with learning disabilities in the Bristol, North Somerset and South Gloucestershire (BNSSG) CCG area reported to the LeDeR programme. The activity data report was previously presented to the BNSSG LeDeR Steering group monthly. As this is the first reporting of activity data in a quarterly version it contains data from Q1 and Q2 2019/20. Future reporting will contain one-quarter activity data only with comparisons to previous quarters where relevant.

The purpose of the activity report is to share the demographic data and the specific improving health outcomes activity data relating to the care provided to those with a learning disability whose death was reported to BNSSG CCG in Q1 and Q2 2019/20.

The report contains the status of the Key Performance Indicators (KPIs) and Key Lines of Enquiry (KLoEs) that relate to the LeDeR reviews, LeDeR reviewers and progress of the LeDeR programme in the BNSSG STP.

The report is aimed at providing assurance to the members of the BNSSG Governing Body on progress with the LeDeR programme within BNSSG.

2. Key Performance Indicators (KPIs) and Key Lines of Enquiry (KLoEs)

The KPIs and KLoEs relating to the BNSSG LeDeR programme are listed below.

- All new cases are allocated within 10 working days to a LeDeR reviewer and have a completed LeDeR review within six months of the notification of the death to the local area.
- Recruit and train more individuals to become LeDeR reviewers to ensure there is a sufficient pool of trained reviewers to enable timely allocation and completion of reviews.
- Establish a 'buddy' support system for new reviewers so they can become confident and competent with their first LeDeR review.
- All completed reviews will be quality assured within two weeks of completion/receipt by the Local Area Contact (LAC).
- Ensure learning is identified from reviews and discussed at the LeDeR Steering Group and assure appropriate recommendations and improvement work is agreed and actioned.
- The CCG will publish data and learning points from LeDeR reviews.

- The CCG will produce an annual report which will be submitted to the Quality Committee and Governing Body demonstrating action taken and outcomes from LeDeR reviews.

The KLoEs relating to the BNSSG LeDeR programme address further assurance required and include:

- BNSSG CCG is a member of a Learning from Deaths Report (LeDeR) Steering Group and has a named person with lead responsibility.
- There is a robust plan in place to ensure that LeDeR reviews are undertaken within 6 months of the notification of death to the local area.
- The CCG has systems in place to analyse and address the themes and recommendations from completed LeDeR reviews.
- The CCG lead maintains a pool of sufficient trained reviewers to enable timely allocation & completion of reviews and reviewers are supported.
- A system is in place to quality assure reviews.
- Family, carers and people with a learning disability are actively engaged with the local area steering group.
- Reviewers are skilled in working with bereaved families .

Evidence of how these KPIs and KLoEs are being met is provided in the following narrative:

In Q1/Q2 2019/20 we have met 5 out of 7 of the KPI's for LeDeR review, with good progress made toward completion of the final two. All actions relating to achieving our KLoEs have been met.

In Q1/Q2, in line with the national picture, BNSSG CCG had 59 2018/19 LeDeR reviews due for completion. This meant that BNSSG LeDeR reviews were not meeting the KPI for being allocated within 10 days or completed within six months of notification.

In March and April 2019 BNSSG CCG used NHS England funding and employed two LeDeR reviewers. The two BNSSG CCG employed reviewers were allocated 35 of the 59 2018/19 cases.

By the end of Q2 2019/20 a running total of 24 reviews had been completed, this was from a total of 84 cases notified to BNSSG since July 2017. In Quarter 1 and 2 2019/20 35 reviews had been allocated and at the end of Quarter 2 24 reviews were requiring allocation. One case marked as incomplete remained open for further investigation.

The KPI trajectory for completing reviews within six months of notification shows an improving picture and is expected to be met by the end of Q4 2019/20.

The KPI requirement for allocating a review within 10 days of notification has not been met in Q1 or Q2 2019/20. This is due to the concentrated work in clearing the open cases and lack of an available pool of reviewers to be allocated cases.

Recruitment of reviewers is in progress. In addition to the two dedicated LeDeR reviewers employed by BNSSG CCG we have recruited four new reviewers in Q1 & Q2. All four reviewers

were recruited from North Somerset Community Partnership (NSCP) following attendance at the peer reviewer focus group held in June 2019 and supported by the NSCP Community Learning Disability Team Nurse Coordinator. Support is required from other providers in BNSSG to increase the number of reviewers available to accept allocated reviews and to enable the requirement to allocate each review within 10 days of notification to be met.

The 'buddy' support system is in place for new reviewers and a peer focus group meets six weekly. The peer focus group includes discussion on the identification of specific training required by reviewers. This has included bereavement training. The Local Area Contact links the reviewer with a "buddy" reviewer when allocating a case. The two reviewers employed by BNSSG CCG have been the main 'buddies' used as they have completed the most reviews to date. A best practice resource pack for completing reviews will be developed by Q4 2019/20 by these two reviewers to further support current and new reviewers.

Completed reviews are quality assured by the LAC within two weeks. Commencing in Q1 2019/20 the CCG has held monthly clinical case review panels. The LAC, the Clinical Lead GP for mental health and learning disability, a safeguarding representative and Local Authority colleagues attend these. This panel provides additional quality assurance, agrees escalation to safeguarding or multi agency review (MAR) and recommends learning to the wider system.

A process for sharing learning from reviews across the wider system has been discussed with local providers. A guideline document has been developed on this process which was discussed at the November 2019 LeDeR Steering Group. The guideline included the proposal that a calendar of 12 learning themes will be created and learning and recommendations from reviews based on this calendar will be presented monthly for discussion at the Steering Group.

The LeDeR steering group has agreed to the production of a quarterly report with an annual report produced and published by the end of Q4 2019/20. A template for the LeDeR annual report for 2019/20 is in development. The annual report will be presented to the CCG Quality Committee and Governing Body in Q4 2019/20 and then will be published on the BNSSG CCG website.

The CCG has established a model for setting up a LeDeR Service User Forum which was presented to the November 2019 LeDeR steering group. Easy read information has been developed to support the recruitment of members with learning disabilities. Initial meetings have taken place with North Somerset People First and there is a plan to attract and widen membership across BNSSG. The service user forum will meet quarterly and provide feedback to the LeDeR Steering Group after their meeting. The LeDeR Service User Forum will have a joint meeting with the Steering Group once a year. The first meeting of the LeDeR Service User Forum was on 5th December 2019. The outcome of this forum will be reported in Q4 2019/20 activity report.

3. Activity Data

The total number of LeDeR review notifications in Q1 and Q2 2019/20 was 26 and 8 respectively. Table 1 below shows the status of the review allocation and those completed during this period.



Table 1: Status of LeDeR reviews Q1 and Q2 2019/20

| | Q1 2019/20 | Q2 2019/20 |
|---|------------|------------|
| Number of reviews notified to BNSSG CCG in quarter | 26 | 8 |
| Number of reviews allocated in quarter | 18 | 17 |
| Number of allocated reviews open at end of quarter | 45 | 43 |
| Number of reviews unallocated at end of quarter | 33 | 24 |
| Total number of reviews completed at end of quarter | 18 | 24 |

Table 2 below shows the demographic data of the cases notified to the BNSSG CCG in Q1 and Q2 2019/20

Table 2: Demographic data of LeDeR reviews notified Q1 and Q2 2019/20

| | Q1 2019/20 | Q2 2019/20 |
|--|------------------|-----------------|
| Number and percentage of males | 18 (69%) | 6 (75%) |
| Number and percentage of females | 8 (31%) | 2 (25%) |
| Number and percentage who died in own place of residence | 5 (19%) | 0 (0%) |
| Number and percentage who died in hospital | 19 (75%) | 6 (73%)* |
| Ethnicity | 22 White British | 8 White British |

*NB the total place of deaths does not equate to 100% due to information not being recorded at time of notification of death.

The demographic data shows that the majority of deaths notified to the LeDeR programme are male. This is similar to the national picture.

The data shows that the number of people with Learning Disability who died in hospital continues to be significantly higher (75%) than those who died at home (19%). The work across BNSSG STP, supported by the Academic Health Science Network (AHSN) to improve health inequalities is aimed at decreasing early death and is hoped will support increasing choice in place of death.

Ethnicity data reporting shows that 30 out of the total 34 notifications in Q1/Q2 2019/20 were recorded as White/British with 4 unknown. This indicates that the correct ethnicity code may not be being completed in the provider records of the person who dies and so not available to the staff member notifying the LeDeR team of the death.

In Q1 and Q2 2019/20, the total number of notifications per provider are shown in table 3 below.

Table 3 showing the number of LeDeR notifications per provider in Q1 and Q2 2019/20

| Provider | Q1 2019/20 | Q2 2019/20 |
|-------------------------------|------------|------------|
| UHB | 7 | 2 |
| NBT | 6 | 3 |
| WAHT | 2 | 0 |
| AWP | 2 | 0 |
| SIRONA | 3 | 1 |
| BCH | 1 | 0 |
| Bristol Council | 0 | 0 |
| North Somerset Council | 1 | 2 |
| South Gloucestershire Council | 0 | 0 |
| Brandon Trust | 1 | 0 |
| Freeways | 1 | 0 |
| Leonard Cheshire | 1 | 0 |
| Milestones | 2 | 1 |
| GP Practices | 1 | 0 |
| CDOP | 1 | 0 |
| RUH | 1 | 0 |
| Shaw Care | 1 | 0 |

The number of notifications received by provider is more than the total number of deaths reported, this is due to some deaths being reported by more than one provider.

Table 4 below shows the causes of death reported for cases reported in Q1 and Q2 2019/20.

Table 4: The number of LeDeR notifications per provider in Q1 and Q2 2019/20

| Cause of death | Q1 2019/20 | Q2 2019/20 |
|------------------------------|------------|------------|
| Cancer | 2 | 1 |
| Dementia | 1 | 1 |
| Gastrointestinal Haemorrhage | 1 | 0 |
| Aspiration Pneumonia | 4 | 1 |
| Bronchopneumonia | 4 | 0 |
| Pneumonia | 1 | 4 |
| Sepsis | 2 | 2 |
| Bowel Ischemia | 0 | 1 |
| Frailty of old age | 0 | 1 |
| unknown | 3 | 0 |

The table shows that the highest causes of death in Q1 and Q2 2019/20 related to aspiration pneumonia, bronchopneumonia, cancer and sepsis. BNSSG CCG has worked in collaboration with

the health inequality improvement work being undertaken by the South West AHSN. This work has concentrated on 3 themes for people with learning disabilities:

- Improving the uptake of the annual health assessment
- Improving the uptake of the influenza vaccination for people with learning disability and their carers and relatives
- Improving the completion of NEWS2 and RESTORE2

BNSSG CCG is working with local providers to complete actions that support the three AHSN themes. This has included attending the AHSN LD improving health outcomes event in April 2019. The CCG also applied for NHSE funding for a small bid to complete a project with local CLD teams to establish LD champions in primary care and care homes across the STP. This project is to train these champions to provide tool kits with resources including improving nutrition, hydration, preventing choking, reducing constipation and how to make reasonable adjustment for access to health and social care services. This project will be implemented in Q3 and Q4 2019/20.

4. Grading of Care

Each completed LeDeR review is graded for the level of care received. This grade is decided by a reviewer and quality assured at a CCG clinical case review panel. The grading is used to decide if a Multi-Agency Review, (MAR) is required or if the review can be closed.

Table 5: Grading of care received in the completed reviews Q1 & Q2 2019/20

| Grading of care | Q1 2019/20 | Q2 2019/20 |
|--|------------|------------|
| 1 = excellent care | 0 | 0 |
| 2 = good care | 9 | 10 |
| 3 = satisfactory care | 6 | 0 |
| 4 = care fell short of current best practice in one or more significant areas | 0 | 1 |
| 5 = care fell short of current best practice and some learning could result from MAR | 0 | 0 |
| 6 = care fell far short of expected good practice and this contributed to the cause of death | 0 | 0 |

The grading of the reviews that were quality assured at BNSSG case panels in Q1 and Q2 2019/20 shows that the majority of reviews evidenced good care. Six reviews in Q1 showed satisfactory care and 1 review in Q2 showed care fell short of best practice. No reviews showed excellent care and no reviews were recommended for a Multi-Agency Review (MAR).

To support consistency with the grading of reviews the quality team have developed guidance for LeDeR Reviewers for allocating a grade to the care received by the person with Learning Disabilities before their death. The guidelines enhance the existing LeDeR guidance for all reviews to follow to support consistency. The guidance is still draft and has been shared with the

NHSE South West Regional LeDeR Leads who are supportive of this approach. NHSE regional leads have shared this was all areas within the South West and have asked for comments and with the view that once confirmed will be implemented across the South West.

To provide further assurance on the quality of the LeDeR reviews, BNSSG LACs have suggested to the NHSE South West regional leads the need for a peer review of completed LeDeR reviews across the south west. NHSE are in agreement and will arrange this in 2020.

5. Learning into Action

The recommendations and learning from the reviews are shared at the BNSSG LeDeR steering group for discussion and recommendations for wider system learning.

A separate Learning into Action report, detailing a proposed model for sharing learning with the BNSSG LeDeR Steering group and across the wider system was presented to the BNSSG LeDeR Steering group in November 2019. A (draft) flow chart (see Appendix 1) shows how the learning from LeDeR deaths is collated and shared.

The proposed model includes six themes that group the learning identified from reviews closed by the BNSSG CCG LeDeR clinical case review panel. The six learning themes are detailed in table 6 below with the number of closed reviews that identify the learning theme (**NB** the CCG case review panel commenced July 2019 so the totals of reviews shown below are those closed in the month up to and including October 2019).

| Learning theme | Number of closed LeDeR reviews |
|---------------------------------------|--------------------------------|
| Annual health checks and action plans | 10 |
| Best interest/MCA and DoLs | 6 |
| End of life care | 5 |
| Record keeping and communication | 6 |
| Physical health care | 11 |
| Reasonable adjustments | 7 |

The main learning themes in Q1 and Q2 2019/20 were:

- MCA understanding across all providers
- Use of IMCA when relative not available
- Standardisation of annual health reviews and sharing with other providers
- Training on aspiration pneumonia
- Reasonable adjustments understanding and implementation including desensitisation

The BNSSG LeDeR Steering group also receives the minutes of the BNSSG CCG case review panels which include specific detail on recommendations and learning.

6. Next Steps

Work continues to support the delivery of the LeDeR programme within BNSSG and includes the following:

- All BNSSG Organisation Leads to take responsibilities for identifying staff within their own organisation and putting these staff forward to train as LeDeR reviewers. This will enable the LAC to have a pool of reviewers to allocate notified reviews within 10 working days of receipt
- All BNSSG Organisation Leads to support the allocation of protected time for their staff members who have trained as LeDeR reviewers to complete reviews
- Embed the process for sharing and disseminating learning from completed LeDeR reviews across the wider system
- Ensure an evaluation process is in place across the wider system to quality assure actions and recommendations from learning have been completed
- The LeDeR steering group to receive feedback from the first service user forum and to be able to utilise this feedback to fully engage the voice of the service user in the BNSSG LeDeR programme.
- Finalise the draft guidance for grading LeDeR reviews and share with reviewers to support process and consistency
- Develop enhanced guidance for holding Multi-Agency Review (MAR) panels to provide more detailed advice, support and structure for the reviewers and the LACs.

7. Summary

The Governing Body held in Q2 2019/20 commended the progress made in embedding the LeDeR programme across BNSSG CCG. This progress included the establishment of the LeDeR steering group in Q4 2018/19 and the development in Q1 and Q2 2019/20 of robust processes to deliver the LeDeR programme. The recruitment of two employed LeDeR reviewers in Q1 2019/20 has significantly increased the number of reviews completed and as a result decreased the time between notification and allocation of cases.

In addition, the increased completion of reviews has enabled the BNSSG CCG caseload review meetings to be put into operation to quality assure all completed reviews. These case panels have enabled learning themes to be identified and actions to be taken to ensure people with learning disabilities have improved access to services and that any health inequalities are reduced. Five out of the seven KPIs have been met and all of the KLoEs. Good progress has been made in recruiting and supporting reviewers but further work is required to recruit more reviewers to be able to meet the KPI for allocating reviews within 10 working days and completing within 6 months. This includes the importance of whole system sign up and engagement with supporting reviewer sustainability across the BNSSG footprint.

Policy and guidelines on completing a MAR and a model for sharing learning throughout the BNSSG wider system are in development. LeDeR cases reviewed to date evidence six main learning themes that have been presented to the LeDeR steering group.

8. Recommendations

The Governing Body is asked to consider the points raised in this report and note the recommended next steps.

9. Financial resource implications

To date the BNSSG CCG has been able to support compliance in the completion of LeDeR reviews using funding from NHS England to employ two dedicated LeDeR reviewers. The delivery of the LeDeR programme would benefit from continued funding.

10. Legal implications

No legal implications associated with this paper

11. Risk implications

The actions taken to date for improving the recruitment and retention of LeDeR reviewers have been successful, but further support is needed from all BNSSG organisations to provide named staff as LeDeR reviewers. Without organisational and whole system sign up and engagement there is a risk to the ability of the CCG to meet the KPI requirement of allocating reviews within 10 working days and sustaining the completion of reviews within 6 months. This will affect the ability of the wider system across BNSSG STP to take and embed learning from LeDeR reviews

The attendance and engagement of all BNSSG system providers and commissioners at the LeDeR steering Group is still variable and not consistent. Emails to provider Directors of Nursing have been sent previously from the Interim Director of Nursing and Quality and LeDeR is now discussed on the providers' quality sub-group meetings. Further individual director level discussions will be held in the New Year.

12. How does this reduce health inequalities

The delivery of the LeDeR programme identifies learning from themes identified from the completion of LeDeR reviews. This learning presented to the BNSSG LeDeR steering group and Quality Committee enables recommendations and actions required to reduce health inequalities for people with learning disability to be completed across the BNSSG wider system.

13. How does this impact on Equality and Diversity?

The LeDeR programme focus is on improving equality and diversity outcomes for people with learning disabilities

14. Consultation and Communication including Public Involvement

Plans for service user involvement in the BNSSG LeDeR steering group are in place

Appendices

Appendix 1 – LeDeR Process Flow Chart



Appendix 1

